Wessex Asthma Network

NHS Portsmouth Hospitals University NHS Trust

ESMENA

Solving your asthma puzzle

ESMENA: Education, Self-Management and Empowerment in exacerbatioN prone Asthma

An education programme for patients with difficult-to-control asthma

We would like to invite you to take part in the ESMENA research study, but before you decide, we would like you to understand why the research is being done and what it will involve.

What is ESMENA?

ESMENA is an education programme designed by both healthcare professionals and patients aimed at improving the care for patients with asthma.

Why have I been invited?

You have been invited to take part because you have asthma and are under the care of the Portsmouth Asthma Service, or have previously needed to see your GP or attend the emergency department for help when your asthma has got out of control.

Do I have to take part?

No; participating in any research project is voluntary. If you decide you do not wish to take part this will not affect your usual NHS treatment in any way.

What does it involve?

If you agree to take part we would collect information about your asthma from you, your hospital notes and your GP records. This will include the treatments you are taking and the number of times you have required an escalation in your treatment.

You will be asked to attend an education session where you will hear talks about how to manage your asthma from a variety of specialists, including a physiotherapist and pharmacist. The session will be informal and interactive with plenty of opportunities for you to ask questions. Due to the COVID-19 pandemic, this may be a virtual session. If it is a virtual session, we would like you to have access to a microphone to ensure you can ask us questions, but it is your choice whether to have your camera turned on or off. The session will likely last three - four hours (the time frame will be guided by your needs).

We will also provide access to an online app called healthinote. This will provide you with summary videos of the main talks in ESMENA, some useful written information and links to other websites.

At the end of the session, we will ask you to give us feedback, for example how useful you found it and how the session could be improved for future patients. Six months after the education session, we will ask you to complete a further feedback questionnaire to help us design future sessions. This will take approximately five minutes to answer and can be completed either electronically or on paper. We will also ask you about your asthma control using standard clinical questionnaires; these should take no more than 15 minutes to complete. If you are attending the asthma clinic, these may be completed during your clinic visit. Otherwise, we will send the questionnaires electronically or in

the post (with a stamped addressed envelope), and will follow them up with a phone call or email if we have not received them back from you within two weeks. A final questionnaire, similar to the six months one, will be sent around twelve months after the education session. These provide us with information about your asthma control for the whole year. Once you have completed these questionnaires, your involvement in the study will finish.

What are the benefits to me?

Our hope is that by completing the education programme, you will feel more confident in managing your asthma. However, as this is ongoing research, we cannot guarantee the education programme will fulfil all your educational needs. We would welcome feedback on how to improve future sessions to make them more relevant and useful.

What happens to the data and the results of the study?

The results of studies are usually published in medical journals. There will be no way of identifying you or your data from the published results. We can send you a summary of the results if you wish.

In this research study we will use information from you and your medical records. We will use only information that we need for the research study. Very few people will know your name or contact details and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it. We will make sure no one can work out who you are from the reports we write. The longer version of this information sheet tells you more about this if you wish to find out more: https://portsmouthtechnologiestrialsunit.org.uk/projects/

What if I change my mind?

You can stop taking part in this study at any time. You do not have to give a reason to the research team if you change your mind. Your normal NHS treatment will not be affected.

Who has organised and approved the study?

Portsmouth Hospitals University NHS Trust is the sponsor for this study.

All research in the NHS is looked at by an independent group of people. The South Central Berkshire Research Ethics Committee (REC reference 19/SC/0005) have reviewed and approved this study.

Will my GP know that I am taking part?

With your permission we will inform your GP that you are taking part and what the study involves. We will also ask your GP for access to their records to collect data for the study.

What if there is a problem?

If you have any complaints about how you are treated during the study, you should contact the research staff who will try address any concerns or problems. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS). PALS can be contacted by phone on 02392 286757 or email PALS@porthosp.nhs.uk.

Who should I contact if I require further information?

For routine trial-related questions during working hours, please contact: 02392 286000 Ext: 4108.

For emergency or non-trial-related medical issues please contact medical services as normal.